

December 31, 2013

The Honorable Governor Brian Sandoval
State Capitol
101 N. Carson Street
Carson City, Nevada 89701

Dear Governor Sandoval:

As chairperson of the Nevada Commission on Autism Spectrum Disorders, I am writing to update you on the activities of the Commission. The Commission met with the representatives from state agencies, parent advocacy groups, providers and other interested parties. Enclosed is an update on progress made on the recommendations from the 2008 Autism Task Force Report and Commission recommendations.

Recent prevalence rates for autism now indicate 1-50 school age children are on the spectrum; we believe the influx of people with Autism Spectrum Disorders (ASD) will impact access for all disabilities, stretch provider capacity, increase waitlists, expenses and the long-term viability of all state programs.

In Nevada, there continues to be gaps in coverage and capacity to address the needs of individuals across the lifespan and spectrum of ASD. Major concerns:

- Medicaid's lack of coverage for evidence-based treatment specific to ASD (ABA)
- Lack of transition services to address the specific needs of ASD population
- Limited to no access to research supported dosages of evidence-based treatment
- Lack of services and supports specific to adult ASD population which support self determination
- Insufficient workforce and staffing issues for autism programs to meet needs
- Housing issues include: personal choice, availability, funding, lack of options specific to ASD
- Awareness about availability of services, where to go
- Safety due to wandering, elopement with ASD population
- Lag between initial concerns, identification (failed screen and diagnosis) and access to research levels of evidence based treatment
- Lack of respite funding
- Coordination of services
- Disparities for critical populations – rural/remote locations, racial/ethnic, low socioeconomic status

During the December 2013 Commission meeting, members voted to support the development of a five-year strategic plan to address the needs of individuals with ASD across the lifespan. Commission members will meet with experts, advocates and others to develop the plan in 2014.

Working together to address the needs of Nevada's Autism community continues to be instrumental. Noted collaborations included: Nevada Leadership Education in Neurodevelopmental and Related Disabilities (NvLead) program at the University of Nevada, Reno teamed up with state and local agencies to improve awareness statewide with the distribution of 55,000 Milestone booklets with Nevada resources contact information.

NvLEND's first class of interdisciplinary trainees (12) completed a one-year training program on interdisciplinary practices for children with autism and other neuro-developmental disabilities; NvLEND also received an additional grant to train Nevada childcare providers on early signs of ASD. NvLEND is currently operating on the second year of a five-year grant from Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB).

The Commission hopes Aging and Disabilities Services Division's (ADSD) Integration Plan will promote collaboration and consistency across state programs for services and data collection. The integration provides our state with the unique opportunity to create a system with increased access and standardized outcome measures. The potential to truly demonstrate the effectiveness of interventions and services could enable Nevada to forecast and improve the outlook across the lifespan for individuals with Autism Spectrum Disorders (ASD).

Advances in screening and diagnosis tools now provide the theoretical capability to identify 95% of children with ASD before the age of 24 months. Clinical trials specific to toddlers have demonstrated the value of early intervention utilizing Applied Behavior Analyst (ABA) with changes in brain EEG activity as well as behavior.

Nevada needs a well-trained professional workforce to treat, conduct screening and diagnosis in our community. Nevada pedestrians need to follow guidelines defined by the American Academy of Pediatrics.

The Commission is pleased to recognize improvements made by Nevada Early Intervention (EI) to provide diagnosis at an earlier age as a result of AB316 and AB345. EI established protocols to meet the requirements. However, the number of children receiving research levels of evidence-based treatment for the age group 2-3 year olds has not improved as indicated by the low number of referrals and the number of children for that age group served by the state Autism Treatment Assistance Program (ATAP). Data provided by EI indicates the majority of the children with ASD served by EI and their Community Partners receive 5 or less hours of direct treatment per week. Research supports at least 25 hours a week.

The earlier in a child's life, treatment can begin the better the outcome. Research has proven approximately 50% of children with Autism who receive early intensive behavioral therapy (ABA), achieve higher educational placement, demonstrate increased IQ levels and will perform successfully in a regular education setting. And have the potential to live independent lives.

When access to treatment is denied, only two percent will achieve that level of success. Without treatment 90% will need some level of lifelong support.

The move of EI and Regional Centers under the direction of ADSD should ensure a coordinated system of care for individuals with ASD. One which promotes and delivers research levels of evidence-based treatment. The Commission recommends children have access to at least 25 hours a week of evidence-based treatment. ATAP should be the path for treatment assistance for children diagnosed with ASD as the infrastructure is established with providers who specialize in ASD. The Commission strongly recommends the Governor's office and ADSD support an option for children to receive assistance through ATAP rather than EI.

ATAP policies and procedures were implemented to support seven different plan types to assist families in providing evidence-based treatment at various levels. Plan procedures are in place to ensure plan targets are met, with data demonstrating program outcomes and life-changing outcomes for the children the program serves. Plans recognize and support transition across plans as the child progresses or as the child's needs indicate the requirement of support rather than treatment. I have included an overview of the plan types.

Governor Sandoval, the Commission is extremely grateful for the increase in state dollars to provide evidence-based treatment to children with ASD. Because of you and Legislators Nevada's Autism Treatment Assistance Program (ATAP) was approved for \$4,080,134 in FY14 (\$3,712,552 for direct services and \$367,582 for personnel and ancillary costs); \$7,653,871 in FY15 (\$7,146,693 for direct services and \$507,178 for personnel and ancillary costs).

The intent was to serve 50% of the ATAP's wait list at the time. The projection suggests 307 children will be active by June 2014 and a total of 572 will be active by June of 2015. Several factors can impact the reality of those numbers. Factors impacting the cost per child, per month include: case mix of plan type, critical behaviors and the goal of supporting plans with base-level research dosages of treatment to 45% of children served.

A study on wandering was presented to the Commission. It indicated nearly half of children with ASD were reported to engage in elopement behavior, with a substantial number at risk for bodily harm. 26% were missing long enough to cause concern. Of those who went missing, 24% were in danger of drowning and 65% were in danger of traffic injury. These results highlight the urgent need to provide intervention and supports to reduce the risk of elopement, to support families coping with this issue, and to train child care professionals, educators, and first responders who are often involved when elopements occur.

In December 2013, ADSD staff provided data to the Commission as required by AB316 and AB345 from School Districts, EI programs, MHDS, Vocational Rehabilitation and ATAP. (attached)

Highlights included:

- 5,145 - The total number of school age children identified with ASD by Nevada School Districts
- 291 – Children identified with ASD by Early Intervention programs
- 191 – Children being served by ATAP
- 575 – Current ATAP wait list and pending wait list status (referral list)
- 9 – Referrals received by ATAP from EI programs
- 205 – Clients with ASD served by Vocational Rehabilitation
- 26 – Clients with successful employment via the assistance of Vocational Rehabilitation
- 65 – Number of children receiving Autism specific funding through the Regional Centers

ATAP staff provided an update which included: wait list breakdown, number of children being served, reported data, budget overview, policy and expansion of staff to address statewide needs. The funding provided during 2012 Legislation supported the development of a data system. ATAP now tracks outcomes measures which include 64 impact targets, IQ, language and adaptive behavior scores on all children. Long-term outcomes will be available in the future.

Data has not been presented to understand the true impact of AB162 (insurance coverage for Autism treatment), however, reports to the Commission indicate there continues to be barriers to coverage and appropriate dosages of applied behavior analyst (ABA). Cited contributing factors included: limited number of certified behavior interventionists (CABIs – paraprofessionals) and low number of in-network providers.

The Nevada Board of Psychological Examiners indicates there is currently 72 Certified Behavior Interventionists (CABIs), 36 Licensed Board Certified Behavior Analysts (BCBAs), and 12 Licensed Board Certified Assistant Behavior Analysts (BCaBAs). These are the only professionals who meet the states requirements to serve those with insurance coverage. The CABIs provide the weekly treatment hours, 72 CABIs full time at 40 hours a week are only capable of providing a total of 2,880 hours per week. Reports indicate insurance is providing 14 hours a week or less of treatment, the average is far less. If insurance companies are providing 14 hours a week per client, insurance would only be able to serve 205 children statewide with the current qualified providers.

Autism prevalence rates are increasing at an alarming rate. The Centers for Disease Control and Prevention (CDC) recently revealed a parent survey update to this rate: Today, 1 in every 50 U.S. school-aged children have an autism diagnosis (March 2013). A full population study in South Korea reported a prevalence of 1 in 38 children, were found to have autism using a direct assessment approach and two-thirds of these children would have been missed using a records-only approach similar to the current ADDM surveillance in the US. (CDC, 2011) About 40% of children with autism do not talk at all. CDC reported in 2009 that approximately 41% of children with a diagnosis of autism also have an intellectual disability.

We are at a critical moment our state's focus must include creating a coordinated system of care for adults with ASD. We can expect a wide variety of functioning levels within youth, transitioning from high school to adulthood due to the lack of treatment and the overall spectrum impact of ASD. Home Community Based Waiver Services (HCBS) will be impacted by the influx of those youth exiting the education system. There is a significant lack of services and supports available to those who will not meet the institutional level of care criteria to access the HCBS or supports provided by Regional Centers.

It is urgent we address our gaps now, to eliminate out-of-state placements. Nevada must create cost-effective options which support community living and employment driven by self determination. Data from a 2012 indicated that individuals with ASD do not achieve better employment outcomes if they participate in sheltered workshops prior to enrolling in supported, community-based employment programs. Job prospects for adults with autism in the U.S. are crushingly bleak. Nationwide, their combined unemployment and underemployment is around 90

percent. Autism Speaks has estimated that during the next 10 years, more than 500,000 young people with ASD will turn 18.

Research shows young adults with autism become more isolated as they age out of educational system and fewer opportunities exist for social and recreational activities. According to a 2011 study, only 56% of young adults with autism in the U.S. graduated from high school, and only 14 percent started college. Jim Ball of the Autism Society Autism says that a majority of young adults and adults with autism are living at home with their parents. A study done in May, 2011, looked at a group of young adults over the long term to see what they did after high school. About 18% were employed, and 14% were in college. The vast majority were in day services, and 12% had no activities at all.

The Commission's adult work group met and focused on the following: housing, employment, training, advocacy, funding, regulations, workforce development and medical care. The chair of the Community Living sub-committee indicated the document produced in 2011 is still valid for relevant recommendations. The chair also stressed the importance of self determination. (attached).

The Autism Commission will have four of the five positions vacant at the end of this year. The terms of three Commissioners, Jan Crandy, Ralph Toddre and Mary Liveratti, expired at the end of the year. One Commissioner, Scott Reynolds, retired from the Washoe County School District and has indicated his intention of resigning from the Commission. We are concerned that the turnover of four of the five Commission positions would be detrimental to the continuity of the Commission. It is my hope that you will maintain myself and Mary Liveratti for another term or for at least an additional year so that terms could be staggered. We ask for your consideration of this request. I would also respectfully ask you to consider appointing someone who has knowledge and is passionate about services for adults with ASD and another who is a Board Certified Behavior Analyst (BCBA) or a Board Certified Assistant Behavior Analyst (BCaBA).

The Commission is proud to recognize and applaud our state for the legislation that has passed to support individuals with ASD. Positive changes are occurring statewide.

Thank you, Governor Sandoval for your continued support of our community. Because of your support, children with ASD have the hope of reaching their real potential.

With hope,

Jan Crandy
Chair

**Update to Governor Sandoval
Priorities for SFY 13
December 2013**

1. Continue funding for autism services in ADSD

Current status: Through your support, the legislature increased funding for ATAP to address the needs of 50% of the wait list children. Nevada's Autism Treatment Assistance Program (ATAP) was approved for \$4,080,134 in FY14 (\$3,712,552 for direct services and \$367,582 for personnel and ancillary costs); \$7,653,871 in FY15 (\$7,146,693 for direct services and \$507,178 for personnel and ancillary costs).

The projection suggests 307 children will be active by June 2014 and a total of 572 will be active by June of 2015. Several factors can impact the reality of those numbers. Factors impacting the cost per child, per month include: case mix of plan type, critical behaviors and the goal of supporting base-level research dosages of treatment to 45% of children served.

In December 2013, ATAP reported 191 active recipients, 395 children on the waiting list. An additional 180 children are currently in the pre-referral/referral status. Average number of days until child is served is 614 days, with the longest number of wait days being 1,279. The average cost per child was \$1,359 per month per child. The majority of children receiving assistance are age 10 and younger.

Current wait list numbers indicate only 54 children ages 3 and younger.

ATAP assists families in funding evidence-based treatment and by design is not intended to be a life-long support program. Individuals requiring a lifelong level of care post treatment should transition to assisted living programs.

Breakdown by plan type were:

- 70 Comprehensive Plans (assists families in providing 25 hours a week)
- 63 Extensive Plans (assist families in providing 15 hours a week)
- 15 Basic Plans
- 10 Social Skills Plans
- 13 Collaboration Plans (assists families in providing 25 hours a week)
- 11 Insurance Assistance Plans
- 9 Transition Plans

2012 status: In December 2012, ATAP reported 135 active recipients and 272 children on the waiting list. Reported the average cost per child was \$1,340 per month per child.

Breakdown by plan type were:

- 55 Comprehensive Plans
- 50 Extensive Plans
- 9 Basic Plans
- 4 Social Skills Plans
- 8 Collaboration Plans
- 5 Insurance Assistance Plans
- 4 Transition Plans

Meeting the need of the increased number of those affected by ASD, our state programs will need more funding than will likely be available through general funds. The Commission recognizes the need to support a recommendation to require Medicaid to provide coverage for ABA as this will provide a Federal match to support ATAP.

2. Continue funding for self-directed autism services in MHDS

During the Legislative Session, we were concerned that the Mental Health and Developmental Services (MHDS) agency did not receive funding specific to autism). MHDS indicated their commitment to continue services for those children being served. As funding is limited, transition to ATAP has been encouraged.

Current status: Number of children currently receiving Autism specific funding is 65 statewide.

- Rural Regional Center - 10
- Sierra Regional Center - 12
- Desert Regional Center- 43

Referrals received by ATAP since July, 2013 from Regional Centers is 11.

2011 status: 96 were being served statewide. Children age out of program at 11 years old.

3. Continue and expand ATAP pilot with the school districts

In FY12, the ATAP program had a pilot with the Washoe County School District for 5 children, 9 years and older. The Commission had recommended that the pilot be continued and expanded.

Current status: Washoe elected to discontinue their collaboration effective fall of 2013 due to funding constraints.

Clark County School District (CCSD) continues to provide home ABA assistance to 110 children through the I.E.P. process. ATAP collaborates with CCSD on 13 of those cases to increase treatment hours to research levels of intensity. CCSD recently signed a contract with ATAP's FMA to eliminate barriers due to reimbursement issues. The new process will start in January 2014. CCSD also provides additional support to children with ASD through a number of specialized programs.

4. Establish an autism track for services

The Commission recommended that an “autism services track” be established in the ADSD. Autism services continue to be provided at three different doors, however now all under ADSD.

- ATAP in ADSD
- Self-directed autism services at Regional Centers in ADSD (Previously MHDS)
- Autism services through Early Intervention Services (EI) in ADSD (previously Health Division)

The passage of AB316 and AB345 has cemented the requirement of policies to support quality data and program outcomes across agencies.

The Commission hopes with all doors now under ADSD continuity and a coordinated system of care across the lifespan and spectrum can be realized for individuals with ASD. Priority given to ensuring children receiving services through EI will have access to evidence-based treatment at research supported levels of intensity.

The Commission requested in the last report to the Governor that ATAP be the permanent track (option) for all EI children with ASD. ATAP has established an infrastructure specific to ASD and is able to provide access to evidence-based treatment. And in comparison, EI data continues to demonstrate their inability to provide research levels of treatment.

As of this date EI and ATAP continue to provide services to a limited number of children with ASD accessing both programs and both programs’ resources.

5. Improve data collection

Data on individuals with autism continues to be limited. The passage and implementation of AB316 and AB345 should improve data collection statewide and demonstration of outcomes. EI continues to indicate problems with their TRAC system to collect and share data specific to ASD as recent as the December 2013 Commission meeting.

Current status: The first round of required data to meet the requirements of AB316 and AB345 were submitted to ADSD to meet the August 2013 deadline.

Documents with data from the following are included:

- Autism Treatment Assistance Program
- Early Intervention Services and Community Providers
- Vocational Rehabilitation
- Regional Centers
- School Districts

6. Improve screening and the age at which diagnosis occurs

Protocols were established to improve screening and diagnosis across EI programs and Community Providers.

Current status: During the last 5 month reporting period for July 1, 2013 – November 30, 2013: Nevada Early Intervention reported 1,056 children were screened for ASD with 331 children failing the screen, indicating autism concerns. 291 new children were identified with ASD by EI and Community Providers. 202 of those children received an assessment utilizing the ADOS, a tool required by AB316 and AB354. State programs administered 182 ADOS statewide.

During a one year reporting period for July 1, 2012 – June 30, 2013: Nevada Early Intervention reported 2,147 children were screened for ASD with 577 children failing the screen, indicating autism concerns. 97 new children were identified with ASD by EI and Community Providers. 59 of those children received an assessment utilizing the ADOS, a tool required by AB316 and AB354. State programs administered 51 ADOS statewide.

7. Improvement of services for children ages birth to 3.

Children receiving services through EI or Community Partners typically do not receive research recommended levels of treatment and continue to have limited access to Applied Behavior Analysis (ABA).

The Commission's Early Intervention Sub-Committee recommended needed intensity and hours of service at a minimum of 25 hours per week of evidence-based treatment.

Current status: Data presented by EI indicated the majority of children receive 5 or less hours per week of direct treatment and did not indicate if it was ABA. The data also demonstrated inconsistent levels across programs. A referral system has been established to track referrals to ATAP as required by regulation. **(NRS 427A.880: Referral to Autism Treatment Assistance Program.** For an infant or toddler with a disability who has autism spectrum disorder and is eligible for early intervention services, the Division shall refer the infant or toddler to the Autism Treatment Assistance Program established by [NRS 427A.875](#) and coordinate with the Program to develop a plan of treatment for the infant or toddler pursuant to that section.)

The Commission's recommendation continues to be the promotion of evidence-based treatment and to provide research supported levels of treatment to this age group.

8. Promotion of evidence-based treatments and appropriate level of intensity for best outcomes.

- a) Continued efforts need to be made to increase funding levels to support research levels of evidence-based treatment.

Current status: The development of the Comprehensive Plan and Collaboration Plan within ATAP to assist families in providing 25 hours a week of evidence-based treatment.

- b) Increase the number of qualified autism service providers – Promote and support the development of programs within the higher education system to increase the quality and the number of autism professionals to serve persons with ASD. Areas identified in the Commission’s sub-committee on Workforce Development included: diagnostics, teacher education, behavior analysts, speech language pathology, occupational therapy and physical therapy.

Current status: NvLEND’s first class of interdisciplinary trainees (12) completed a one-year training program on interdisciplinary practices for children with autism and other neurodevelopmental disabilities. Second class has started. UNR and UNLV offer BCBA coursework, UNR offers BCaBA coursework. Both Universities offer the Autism Endorsement coursework to educators. UNLV is in the process of developing CABI coursework with fieldwork in collaboration with Southern Nevada providers.

- c) Empower families with knowledge through education and training to take an active role in their child’s outcome.

Current status: ATAP’s established policies and procedures ensure parent/caregiver training takes place monthly for participating families. EI protocol includes distribution of the “100 Day Kit” from Autism Speaks which includes information about treatment.

- d) All children with ASD should have access to evidence-based treatment at research levels of intensity to reach their best outcome.

Current status: Available data indicates a total of 191 children are receiving evidence-based treatment through the assistance of ATAP. 79 of those children are utilizing Comprehensive and Collaboration Plans to receive documented 25 hours a week. CCSD is funding ABA hours for 110 children beyond the school day.

9. Improve medical insurance coverage access for autism.

Current status: Insurance coverage is typically providing 12 to 14 hours per week of ABA. The exact number of children able to access this coverage is unknown at this time. However, it can be estimated utilizing the number of certified behavior interventionists (CABIs) certified in Nevada at this time. CABIs provide the weekly treatment hours as directed by the supervising Board Certified Behavior Analyst (BCBA). There are currently 72 CABIs. 72 CABIs working full time at 40 hours a week are only capable of providing a total of 2,880 hours per week. Reports indicate insurance is providing 14 hours a week or less of treatment, the average is far less. If insurance companies are providing 14 hours a week per client, insurance would only be able to serve 205 children statewide with the current qualified providers.

Reported barriers continue to limit access.

Barriers include: Knowledge of system and coverage, limited in-network providers, limited number of certified behavior interventionists, prescribed levels of treatment, insurance companies denials, and limited number of providers pursuing insurance in-network status or insurance reimbursement. In December 2012 The Board of Health determined HPN's network was inadequate. HPN added one provider in the north, but network remains unchanged in the south.

10. Improve services for Adults with ASD

Current status: Insufficient ASD specific infrastructure for the youth-adult population. Lack of funding, supports, housing and services specific to meet the needs of adults with ASD. The Commission's Sub-Committee made recommendations to address Community Living, Services and Employment for Adults with ASD with priority given to support an Adult Waiver. The report with recommendations created in 2011, remain relevant today. The development of the Five-year Strategic Plan hopes to address a coordinated system of care for those across the spectrum. Leveraging existing infrastructure to create a plan type specific to support comprehensive solutions creating a continuum that builds on what systems exist already. Discussion of a pilot within ATAP to establish specific to the population who will not meet the institutional level of care criteria to access Home and Community Based Services Waiver. This would require a change in regulation to increase the age limit of those ATAP serves.

The influx of individuals with ASD aging out of the education system will impact state services and wait list for HCBS.

The Commission will concentrate on promoting the recommendations made and request legislation to support self determination and solutions to address services and supports for adults with ASD.